

Preparing Young Adults with Sickle Cell for Adulthood
Request: \$50,000

Description of project: Prisma Health's Children's Hospital's Center for Cancer and Blood Disorders team treats 650 children and young adults with Sickle Cell Disease (SCD) annually, of which approx. 100 are age 18-21. Preparing teens and young adults with SCD for adulthood needs to consider the unique psychosocial and biomedical factors that pose challenges to learning to manage their medical condition. CAMP KEMO Programs is the sole supporter and provider of the psychosocial services offered to those patients in conjunction with their designated medical care team. Our team seeks to add support and educational opportunities for these young adults to better prepare them to transition to adult providers and manage their condition in adulthood.



SCD disproportionately affects African-Americans and these families often require an adult to stay out of the workforce to help address the frequent medical needs of the child, further exacerbating the population's number of families near or below the poverty line. Many families report a lack of trust that health care providers will understand and properly treat pain and other common complications. SCD pain has a long history of being underappreciated and undertreated in most medical settings due to a wide range of factors. CAMP KEMO Programs works within the care team to build relationships with families which positions us as the primary entity for engaging with youth and families around the issues of transitioning to adulthood.

As advancements have been made in treating SCD over the last four decades, it is thankfully no longer a fatal childhood disease in high income countries; rather, a lifelong chronic condition. As noted by Stuart L. Cramer, D.O., Aflac Director, Prisma Health-Midlands Children's Center for Cancer and Blood Disorders and cited in literature, health care systems across the country are grappling to catch up in preparing young adults with SCD to manage their disease in adulthood. Improved management as adults includes educating patients and the health care providers that treat these patients in recent advances in pain management (the most common and debilitating complication for adults with SCD), teaching youth fundamental skills in self-advocacy that are needed in adult care settings, and increasing patient knowledge and preparation to manage the financial and insurance issues, giving these youth the best opportunity to thrive in adulthood.

In addition to providing care in the greater Columbia area, CAMP KEMO PROGRAMS provides psychosocial services for sickle cell patients in Orangeburg, Florence and other outlying communities.

The CAMP KEMO Programs team proposes to meet this need by adding educational and supportive programming, outlined below:

- Salary support- The science of pain management has become more holistic and includes a range of health behaviors, behavioral pain coping skills, and social supports in addition to pain medications and other medical treatments. CAMP KEMO Programs psychology team have developed and pilot-tested new programs for providing patient and family education about current best practices in pain management (estimated at \$20,000)
- Two weekend retreats for patients -These retreats will involve a combination of educational programs and skill-practice activities to improve the youth's understanding and skill level for self-advocacy in health care and the financial/insurance issues they will need to manage as adults (estimated at \$20,000)
- Dinners for parents and patients to help them understand transition (estimated at \$15,000). A major focus of our approach is to work with parents and patients from preteen years so they can understand our transition program and support our efforts with similar messages to youth about the knowledge they will need as they age.

CAMP KEMO Summer Camp Support
Request: \$50,000

Description of project: CAMP KEMO Programs seeks funding to offset the expense of the use of a new facility. South Carolina previously only had two rental camp facilities available in the summer. Serving an average of 150 campers and 75 overnight staff CAMP KEMO requires significant facility space to be able to provide the vital programming we are best known for. Additional considerations must be made to keep our most fragile immune compromised patients safe, while still allowing them the opportunity to have a break from their treatments and just be kids for the week.



For the last 7 years CAMP KEMO has rented a facility in Honea Path, South Carolina, roughly 2 hours from our home medical center, volunteer and donor base in Columbia. This caused notable hardship in volunteer and donor support which CAMP KEMO solely relies on to provide life changing experiences for children with cancer and their siblings.

In 2022 CAMP KEMO had the opportunity to move back to the midlands. This move was vital to the continued success of our program and safety of our campers. Having access to a state of the art, ADA approved, and American Camp Association accredited facility while being within 30 minutes of our home medical treatment center brought significant improvements to our services. This move came with considerable cost increase. With a full camper roster, our new rental facility will cost double our previous rental fees. CAMP KEMO Programs is seeking \$50,000 to cover the added cost to the rental fees for CAMP KEMO's facility.